



ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

A Nurse Researcher's Perception of Metropolitan Community Church

*By Mary Elizabeth O'Brien,
Ph.D., R.N.*

I have to begin by telling you a story. A few weeks ago Rev. Dr. Perry called and asked me to be on a panel at the Gay and Lesbian Health Foundation Conference. He told me a little about the evening - that he wanted me to speak for about 15 minutes and of course I said yes. Then near the end of our conversation he said, "Now Mary Elizabeth, I want you to TESTIFY!", well, I panicked! I thought "Oh my goodness, now what do I do!" For those of you who were not raised in the Roman Catholic Tradition you may not be able to fully identify with my anxiety, but the "Baltimore Catechism" does not teach one how to "Testify!" Catholics may 'do windows' but they don't 'do testifying' - especially not Irish Catholics! So I decided I'd just have to put it in the hands of the Lord and hope I got inspired to "Testify!"

Right after I finished talking with Troy I had to leave my office to conduct one of my HIV research interviews, with an MCC church member as it happened, and I thought perhaps I could think about "Testifying" while driving. However, since I knew I'd be hitting heavy downtown Washington traffic, I decided that the better part of valor might be to listen to some music so I put a cassette in my tape deck which had been given to me by a study team member. It was music that I had never heard before - the original score from the play, "La Cage Aux Folles." I was totally enchanted by the music - some of the songs are so tender and poignant - but the one that touched my Spirit the most (I'm sure many of you know it) was - "The Best Of Times Is Now" - I kept listening to the refrain over and over; "Hold to this moment fast and live and love as hard as you know how!" - and suddenly I knew that that's what I wanted to tell you about tonight. To testify about - the loving as hard as they know how that I have experienced in my contact with members of the Metropolitan Community Church. It seemed to me that this was the message which I have learned from the Metropolitan Community Church and indeed is the message of Christianity itself. As the Rev. Dr. Perry reminds us in "God, Gays And The Gospel," Jesus gave us the greatest commandment: To Love! As I said earlier, they don't teach you how to testify in the Catholic tradition and I don't want to let Troy down but I thought that since another message which I have heard very loud and clear from the MCC Church (and also from La Cage) is "Be Who You Are," that maybe I should speak to you As Who I Am --

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Editor: Rev. Dr. Stephen Pieters

A Nurse Researcher, and share with you some of the data - the real life empirical observations which I have gleaned during my interactions with MCC - some day to day vignettes as it were in the life of the MCC. (My thoughts will be related specifically to the Church's AIDS care-giving ministry as this is the work I know best.)

Although I have heard some magnificent sermons in the MCC and I know that these messages are critical to inspire us to action, I have to confess - and probably again it's because of my being a researcher - that I am even more moved by the "Deeds" which I have observed. Now! One of the other problems some of us Catholics have is we're not very good with scripture, so I called the Associate Pastor of MCC/DC, Rev. Candace Shultis, for help and said, "I have this idea but I think I ought to have some kind of scriptural basis for what I'm going to say so what's that stuff about the 'vine and the branches' - you know, the 'bearing fruit business'?" She said, "I think you mean Matthew 7:20 - 'By their fruits you shall know them.'" Well it is indeed by their fruits that I have come to know the magnificent Christianity of the MCC Pastors, Deacons and Members! First of all I want to disclaim a rumor. I don't know how widespread this rumor is in the gay community or the straight community but one of my study participants told me that he had heard, and sort of believed, that quote "Gay" Churches (churches ministering to the Gay community) weren't real churches; that they were more like social clubs or as he rather colorfully put it "cruising spots" - speaking as a sociologist as well as a Christian, that's definitely not the case with MCC as I believe my vignettes will demonstrate indeed. My study participant's words provide the evidence. He said, "I came to cruise and I stayed to worship."

I can truly understand someone staying to worship at MCC. The worship services have a kind of sweetness and gentleness about them - they remind me of the first line of a beautiful old hymn which though not of my tradition I have come to love: "There's a Sweet, Sweet Spirit In This Place and I know That It's The Spirit Of The Lord." I found in MCC a place where I could bring persons with HIV disease or AIDS to worship services and trust that they would be treated with love and with respect and with dignity - that no one would be afraid to touch them or hold them. This fact alone endeared the church immediately to my Nurse's heart. I didn't need to examine the Church's organization, the credentials of the Pastors, or their theology. I experienced MCC's theology lived out in response to those in need!

I've gone on hospital visits to persons with AIDS with the Pastors or Deacons and observed first hand such tenderness and caring. This past Christmas Day I had the blessing and I don't use that word lightly or to make it sound romantic - it really was a blessing of visiting in the hospital room of a young deacon candidate who was very ill with multiple opportunistic infections - he had also been one of the first church members to volunteer to be in our study. I was there with a group from the church the Pastor, Rev. Larry Uhrig, the Associate Pastor and several deacons. We laughed a little, we cried a little, we prayed but I think the best part of the experience was that we shared - we shared the pain of the illness and that made it not quite so heavy but we also shared the grace and the beauty and the strength of our young deacon's response to what was happening to him and that was life giving and energizing.

I've made a number of home visits to persons with AIDS with one of the deacons, Bob Smith. Bobby happens to be one of the people I love and respect most in this world - once when I said to him, "Bobby, how do you do the Church's AIDS Ministry day after day, week after week and now, year after year?" His response was, "Oh but it's such a privilege!" A few weeks ago we went to visit a young church member who was bedridden - the KS-CMV - all those awful initials we have had to become so intimate with, had taken their toll - he was sort of depressed, and angry and frustrated when we first got there - he could no longer walk - he had to be carried up and down the stairs. I watched as Bobby gently listened and soothed him and joked a little and I saw his spirits visibly lifted; and as I knelt on the floor while our deacon gave him communion and tenderly held him and prayed with him, I knew beyond the shadow of a doubt that Jesus was in that room! And I knew what Bobby meant about privilege! And I learned about "Loving as hard as you know how."

Another anecdote which I think magnificently exemplifies Matthew's concept of bearing fruit involves two of my other study participants, also both MCC members - very ill with AIDS. The two were partners and it had come to that situation HIV+ couples so often fear - what if both of us get sick at the same time? They did. One day a crisis occurred. One had fallen and his partner didn't have the strength to lift him. They called the church for help and another of the MCC deacons, Leon Hampton, together with two other church members left their jobs and went to them. Leon, who is also one of my precious heroes in this world, carried one of the men in his arms down to a car and got him to the hospital. When he was cared for, Leon and the church members went back to the apartment to care for the other partner and spend the rest of the day cleaning and washing clothes - catching up on all of the daily life needs that the couple had been too ill to handle for some time. And this caregiving continued for weeks. When I told Leon how moved I was by this kind of caring, he just looked at me and said, "But Mary Elizabeth, that's what Jesus tells us to do as

Christians." All I could think of was when St. Peter is totalling up the grade point averages to determine who gets into heaven, I hope I'm not competing against a curve set by the MCC deacons.

I could go on and on with stories such as these but I thought I'd end by sharing a couple of thoughts from Church members who have told me during the course of their study participation what their faith and the MCC church has meant to them. These comments are also from two people I love a lot. Both have lost their spouses to AIDS and are now facing their own futures with HIV+ positivity. One said, "I can thank God that he set Daniel free, and I thank God that one day he knows when I also will be free and we can be together again. I don't have to wait to die to be spiritually alive. I already am. HIV does not own my spirit. AIDS will never take away my life." And I've abstracted several special lines from a poem by my other friend which he wrote in memory of his spouse Freddie: "I washed him and held him and told him of my love. I let him go. Hurry not my heart to learn of life and I will feel at times I choose to have him here with me." Surely this exemplifies the concept of "Loving as hard as you know how."

As I was trying to think how best to summarize my thoughts this evening it seemed appropriate to quote some thoughts from the introduction to a small book of meditations for all of us living with AIDS called, "The Color of Light." We give this book to all of our study participants. In his introduction the author Perry Tilleraas cites the American Indian concept of the Heyoehkah - or sacred clown - a person who did things differently - who challenged people's thinking. The Heyoehkah walked and danced backward to show that there could be a different way to do things. Tilleraas asserts and I agree that there has been a "Heyoehkah" response to AIDS from the Gay community and I have especially experienced that response in the Metropolitan Community Church. So, I will paraphrase Perry Tilleraas' words, relating his thoughts to MCC: When the normal response to AIDS would have been fear and panic, the MCC responded with love and trust; when the normal reaction to the diagnosis could have been stigma and isolation, MCC brought their loved ones with AIDS into the center of the community and surrounded them with concern and caring; when the world began to chant a death mantra, our Heyoehkah of MCC danced the dance of life; whenever it got dark, they turned toward the light and finally when people said there is no hope, they said: There is always hope!

As a Nurse Researcher working as an Advocate for persons living with HIV infection and AIDS I thank God and the Rev. Elder Dr. Troy Perry with all my heart for the gift of having given birth 21 years ago to the Universal Fellowship of Metropolitan Community Churches.

(Reference: Tilleraas, P., The Color Of Light, Daily Meditations For All Of Us Living With AIDS. Center City, MN, Hazelden, 1988)

AIDS: Perspective of a Black Woman as an Epidemic Among The Myriads

By Sallie Perryman
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Sallie Perryman's perspectives on AIDS have not evolved from research or scientific data but by watching four of her family members die with knowledge that she too has been exposed to the virus.

In her speech at the opening ceremonies of the Sixth International Conference on AIDS, she acknowledges AIDS is waging a vicious attack on the cities of this country, and has seen that same area under siege with drugs, crime, poverty, violence, and homelands. Each of these social ills have continuously plagued the inner city communities.

She is currently employed by Health Research, Inc., as a Special Assistant to the Director of Policy to the AIDS Institute for the State of New York. She is a member of the Board of Directors of the AIDS National Interfaith Network and a member of Family and Friend AIDS Network and has investigated AIDS discrimination complaints for New York's human rights office. Ms. Perryman is one of the storytellers in the 1990 Academy Award-winning documentary "Common Threads: Stories From the Quilt."

I feel fortunate to have been asked to participate in this monumental event.

I also must acknowledge my concern for the injustice that has caused many of my colleagues to boycott this event, and, as I applaud you in your efforts, I also must applaud them too. In no way do I want my presence here to be interpreted as a lack of zeal for the methods of protest they have elected to pursue.

The reasons I have elected to stand before you, in spite of the boycott, are a result of the perspectives I have developed around AIDS. I choose to speak, in all consciousness, of my purpose to do whatever I can whenever I can, and with the realization I may not have an opportunity such as this again.

Before sharing my personal perspectives with you, I'd like to tell you how they have evolved.

I am an American-born, Black woman, born and raised in the urban setting of Brooklyn, New York. Brooklyn has one of the highest seroprevalence rates in the United States of America. It, like most urban high seroprevalence areas, has a high incidence of drug abuse for both intravenous drugs and crack.

My late husband was an intravenous drug user. When people think of a drug addict, they think of a person sitting and nodding, with saliva drooling out of their mouth, and scratching lethargically. My late husband, however, held a full-time job and was a caring and loving man, who contributed to his society and his family. When we had been married three months, he approached me, seeming very burdened and remorseful and confided to me that he was a drug addict. He was concerned that his addiction would hinder me and gave me the option of separation and/or divorce. He told me how frustrating and painful it had been not having control over his life and he realized that because he felt out of control it would sour our relationship. I reminded him that we had made vows to one another, before God, and that pledge had been for better or worse. I told him that this situation would have to get better. We both believed in the power of God to change a bad situation into a good one.

Even though he had been frustrated, over and over again in the past, in his efforts to kick his "habit," he never gave up. He had gone into a detox. He went on methadone. And he went from one drug program to another, but nothing seemed to work. For the first five years of our marriage, we were constantly on a roller coaster in our struggles with his addiction.

In 1980 our first and only child was born. We went through Lamaze classes together and my husband and daughter began to bond with one another before her birth. After she was born, he would wake up in the middle of the night with her. He changed her diapers; he bathed her, and literally worshipped his daughter. They were inseparable. When she was about two years old, we started her in the daycare center where he worked and that just further cemented their bond. It was at this point in his life that he became more motivated to change and discovered Narcotics Anonymous. He learned to be sober, one day at a time, and went to meetings--fanatically--taking his toddler with him when he went. He had been drug free six months and we were elated.

Then he started to develop fevers and night sweats and complain about body aches and pains. One of his friends took him to the hospital, directly from a Narcotics Anonymous meeting and he stayed there ten days without ever receiving a diagnosis. He was released when his fever finally subsided. That was the beginning of my husband's bout with HIV infection and with the health care system. He went to six different hospitals and various other health care providers in the following two years, without ever receiving a diagnosis.

At the same time that this was occurring in our lives, my husband's older brother, who was a dancer and a gay man, had been diagnosed with AIDS and had become debilitated by it. My husband began to notice similarities between his brother's symptoms, other recovering addicts with him in the Narcotics Anonymous' rooms, and

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AIDS: Perspective of a Black Woman...(Cont'd)

himself. He began to acknowledge that this was not happenstance. My husband more aggressively sought knowledge of his circumstances without avail. His health continued to decline.

It was at this point we began to feel the economic effect of AIDS and how one's economic position was crucial to the type of health care one could access. My brother-in-law, who was in Actors' Equity had good health insurance coverage, access to better hospitals, health care attendants, buddies, ambulance service, and--most importantly--received a diagnosis so he could obtain Social Security.

My husband laid at home, in bed, with his mother and myself taking shifts feeding him and assisting him with his other needs until he got on public assistance and ended up in an overcrowded city hospital...in hospital situations where health care providers failed to feed him and wash him when he was unable to do this for himself.

I began to see how socially, if you are an intravenous drug user, you are perceived to be inherently evil and parasitical, despite what your values actually are. You are perceived to be guilty of all the stigmatizing behaviors associated with drug addiction.

Politically, I realized that the mobilization of gay, white America, who came together around the threat of AIDS in their community, could not be replicated in a community where AIDS is only one of many issues. Issues of crime, drug abuse, poverty, and racism, which all have been promulgated in urban communities, take precedence over AIDS.

I watched my husband as viral warts began to flourish on his hands, feet, and genitals. I watched as he developed dental problems and thrush. I watched him go from 170 lbs to 80 lbs, the last time I took him to the hospital.

I also watched my mother-in-law as she buried three sons in an eighteen month time period. One who died of AIDS, one who was suspicious that he had AIDS and died from a drug overdose, and my husband who was posthumously diagnosed with AIDS-related complex. Two years later I watched as she buried a daughter-in-law also due to AIDS. At that point, I realized that an entire generation of men had been wiped out in my family. Since then I've seen that pattern repeat itself in many other families in my neighborhood.

As the AIDS epidemic continued to take its toll in urban America, and the epidemiology become more apparently hued by impoverished racial and ethnic people whose lives are already under siege, its effects can only become more violent in its attack. Families are now under siege in a devastating and unrelenting assault.

Since my husband's death, I worked fighting the kinds of discrimination that has surfaced in accessing health care, child care, housing, and credit at the New York State Division of Human Rights. I've got to take a stand against the same kind of prejudice that won't allow

persons with HIV infection into a country simply because of their perceived disability and that runs the risk of stigmatizing people, so that they are set up to be ostracized by their peers and the systems that control their very livelihood.

More recently, during my employment at the AIDS Institute in New York I've watched the Federal Drug Administration through its blood donation policies stigmatize an entire community of our country's newest immigrants because of their nationality. I've watched as this government has denied its very own citizens access to the very same institutions that once were their means of fleeing poverty such as the Armed Forces, the National Guard, and Job Corps because of their HIV status, without creating new options. I further watched as clinical trials omitted intravenous drug users, women, and children from their ranks and focused on gay white men because they were more economically and politically empowered.

I also listened as I heard it be proposed that women of child-bearing age postpone pregnancy or that HIV-positive women consider averting their pregnancies, knowing that the infant mortality rate for Black people in the United States is two times that of the white race and cognizant also of the fact that for every single infected child averted, to limit the transmission of AIDS, two healthy children would be eliminated. I ponder what the reality of such a proposal will mean if applied to me and my family, where an entire generation of men have ceased to exist. And yet, much of my community is still in denial.

My perspective of AIDS is one in which there is a massive waste of human potential due to capricious and arbitrary policies that give more credence to money than to life itself. My perceptions of AIDS are colored by the reality of the homeless who sleep in the subways I travel and the front page of a local newspaper that portrays images of Black toddlers just beginning their lives, alongside inscriptions that read: "The Children of the Damned." My perception of AIDS is one where homophobia, racism, and sexism run rampant and life-sustaining forces are denied because of varying ideologies and economics.

Yet, my perspective is not one of defeat. As with every other facet of my life, it has become one of struggle and commitment. Commitment not only to those of us infected by the virus, but also out of a concern for humanity as a whole. A commitment to guarantee the ideals of life, liberty, and pursuits of happiness which this country purports must be guaranteeing remedies for the economic, political, and social ills of this society out of which this medical crisis has grown.

I believe the resources to effect such a task are present both in this arena, and in the collective efforts of those congregated outside in protest and in my community. I believe with the guidance of God--victories are being won and will continue to be won in spite of AIDS.